
At the coalface

Unproven treatment in childhood oncology – how far should paediatricians co-operate?

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Authors' abstract

Parents of children with terminal illness may try many different types of alternative and unproven treatment, not all recognised by the medical establishment. When active participation is requested difficult ethical dilemmas may arise. We present one such case, a child of five years with an inoperable posterior fossa brain tumour.

Case history

Robert, a five-year-old boy was admitted to hospital with severe stridor. He had had a hoarse whispering voice for three weeks and been given antibiotics by the GP. At 4 am on the day of admission, he woke up with noisy breathing which gradually worsened during the day. He was brought to casualty at 6 pm and in view of the severe airway obstruction, was intubated. The narrowing was so severe a 3 mm endotracheal tube was the largest size that could be passed. Marked redness and swelling of the epiglottis and sub-glottic region was noted. A gram stain of secretions showed gram positive cocci and he was given Penicillin, Flucloxacillin and Chloramphenicol. After three days in the intensive care unit he was extubated but rapidly became strident and was re-intubated this time with a size six nasotracheal tube. In view of failed extubation, he was started on Dexamethasone and successfully extubated on day nine of his admission. He was transferred to the paediatric ward and discharged three days later on medication for his pre-existent asthma (nebulized terbutaline 500 mcgms and budesonide 200 mcgms, both twice daily).

He was reviewed two weeks later. A nasal speech pattern, similar to that of a child with a cleft palate had persisted since discharge. He was eating well and there were no other symptoms. An X-ray of the post-nasal space showed enlarged adenoids with no other abnormality.

He was referred to the Hospital for Sick Children, London. A Computer-assisted Tomography (CT) scan showed an extensive posterior fossa tumour

distorting the floor of the 4th ventricle and extending downwards into the cervicospinal cord to the level of C4/5. A stereotactic biopsy was planned but unfortunately his condition deteriorated and he required urgent steroid therapy. Radiotherapy was initiated and a later Magnetic Resonance Imaging (MRI) scan confirmed the presence of a largely intrinsic brainstem tumour extending downwards into the upper cervical spinal cord.

The parents were informed that despite radiotherapy the prognosis was hopeless and that there was no further useful medical treatment. They sought further advice and discovered a medical practitioner in the USA who felt he could possibly help or cure the child. This treatment involved the administration of anti-cancer agents called 'antineoplastons', peptides which the medical practitioner claimed to have an anti-tumour effect and which he had been researching for 15 years. Information was provided from the practitioner's clinic regarding this treatment, which included a list of publications in minor biochemical and oncological journals and a *curriculum vitae* of the researcher, detailing his considerable experience and expertise in the field of cancer research. The father investigated this fully and together with Robert's mother decided to pursue this approach. As these drugs could only be administered through a central venous line they requested that this be inserted in the UK for financial reasons. They also requested the supply of intravenous administration equipment.

Discussion

This case raises the difficult issue of how far doctors should co-operate with unproven treatments. Paediatric oncologists and neurosurgeons had deemed Robert's tumour to be inoperable and had no treatment to offer. It was explained to the parents that despite radiotherapy, Robert would die as a result of the tumour. The parents found and wished to pursue an unrecognised form of treatment and asked for the insertion of a central venous line and provision of intravenous administration equipment.

It was very difficult to assess objectively the possible benefit of the proposed treatment.

Key words

Children; oncology; unproven treatment.

Paediatric oncologists and neurologists were certain that the treatment offered no possibility of cure. None of the publications reported any acceptable clinical trial of treatment and by these standards, the treatment had to be regarded as unproven and probably ineffective. The parents were aware of anecdotal reports of cure and were prepared to try anything, particularly as the peptides were reported to be free of toxic side-effects. 'Today's unproven treatment might be tomorrow's standard therapy.' Robert's parents did not feel that classical statistical analysis was relevant to them. If their child were to be one of the anecdotal cases they would not obviously be concerned about the overall statistical chances of cure from this treatment. They were very keen to embark upon this course despite the considerable expense it involved.

If our co-operation involved no harm to the child with *possible* benefit the only ethical argument against the treatment might be the use of limited resources on unproven treatments. The hospital agreed to fund the equipment for administration of the treatment, albeit for a limited period. There was, however, little ethical debate on this point.

For Robert, however, insertion of a central venous line would carry a risk. Should members of the medical profession therefore involve themselves in this treatment when there would be the real risk of sepsis, the risk of anaesthesia (particularly in view of the past history of severe airway obstruction) and discomfort and pain for the child? It might be argued that the role of paediatricians should be to protect the child from this form of therapy if they felt it held out no hope of cure or palliation. When caring for children we usually accept that parents should choose the course of action that they regard as best for their child. This role may be transferred in cases where child abuse is deemed to have occurred. In these circumstances, health professionals apply for the care and control of a child to be transferred to an alternative agency (the local authority or a judicial court). Is this such a case? In simple terms the proposed treatment might be considered a form of child abuse.

We explained to the parents that treatment was unlikely to cure or palliate and discussed Robert's

position and how he would be the individual suffering the pain and possible post-operative complications.

We participated and co-operated with the parents because there was *no* scientific evidence that the treatment did not help the condition (although we accepted there was no scientific evidence the other way either). We wished to help and support the family through what was going to be a very difficult time and felt withdrawal of our care would leave the family in a much worse position. It was also likely that had we refused they would have found another practitioner willing to co-operate. We also recognised that the central venous line might help to improve terminal care and allow Robert more time at home if the treatment was unsuccessful.

Conclusion

An indwelling intravenous catheter was inserted under general anaesthetic. The airway problems were worsened by this procedure although not to the point of requiring intubation. Robert also developed shingles in the immediate recovery phase, which delayed discharge. He travelled abroad for the initiation of this treatment. On his return the hospital agreed to fund the costs of intravenous administration equipment for an initial period of three months at the end of which the child would be reviewed with a repeat MRI scan to assess the effect of treatment. Unfortunately treatment failed and he died in hospital shortly afterwards. The venous line allowed further time at home when his swallowing deteriorated and he could no longer drink. This article is dedicated to his memory. It is a tragedy that a child so young should die but his courage and the love and caring of his family touched and taught all who looked after him during his illness.

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